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Cancer patients' access to cancer services

1. Introduction and conclusion

1.1. Purpose and conclusion

1. This report concerns the regions and the Ministry of Health's approach to cancer services in the period from 2013 to 2017. Rigsrevisionen initiated the study in November 2017.

2. Outcomes for cancer patients have improved the past 15 to 20 years, which means that the proportion of people surviving cancer has increased significantly. However, cancer is still the most frequent cause of death in Denmark. Approximately 30% of all deaths are caused by cancer, i.e. approximately 16,000 people die from cancer every year. The survival rates of cancer patients improve, if their cancer is diagnosed early and treated without delay. It is therefore essential that cancer patients are diagnosed and treated as early as possible.

Diagnosis and treatment
The purpose of a diagnostic investigation is to arrive at a diagnosis, describe the disease and offer relevant treatment.

The Ministry of Health monitors progress in cancer services through maximum waiting times and medically recommended standardised cancer patient pathways (CPPs) included in the so-called cancer packages. Maximum waiting times for diagnosis and treatment are a patient right, and with a few exceptions the targets set apply to all cancer patients and are independent of the CPPs. The CPPs are disease specific and based on medical assessments of how standard cancer patients diagnosed with the same type of cancer can get through the pathway as fast as possible without unnecessary delay.

Maximum waiting times
Maximum waiting times are statutory, and they are, with a few exceptions, the same for all cancer patients. Maximum waiting times have been determined for the various stages of a diagnostic and treatment pathway. If the maximum waiting times cannot be met, the patients must be offered other options.

3. Maximum waiting times for diagnosis and treatment were introduced in 2000 with the first national cancer plan, which was succeeded by three additional national cancer plans in 2005, 2010 and 2016.

CPPs were introduced in 2008 and have been monitored on a national basis since the 4th quarter 2012. The cancer plans have led to the launch of several initiatives and extra funding for the cancer area in addition to the funding that is allocated to the regions in the annual finance acts. Moreover, the introduction of the political initiative *The sooner – the better* in 2014 released funding of DKK 1.2 billion in the period from 2015 to 2018.

Cancer patient pathway
A cancer patient pathway (CPP) is a plan that sets out the steps of diagnostic procedures and possible treatment. The purpose is to standardise the pathways and avoid unnecessary delays. The pathways differ according to type of cancer. In Denmark, patients have access to 32 tailored CPPs.

The cancer plans and *The sooner – the better* initiative have also had focus on the components of the pathways where the maximum waiting times or CPP time frames do not apply; the time before the patients receive a diagnosis and treatment in a hospital (early detection) and the period after the patients have been treated (follow-up care).

4. The purpose of the study is to assess whether the regions ensure and the Ministry of Health supports timely access to cancer services for patients that are suspected of having cancer or have been diagnosed with cancer. The report answers the following questions:

- Are the regions supporting and is the Ministry of Health following up on early detection of cancer patients in general practise?
- Are the regions ensuring and the Ministry of Health supporting compliance with the consolidated act on maximum waiting times?
- Are the regions ensuring and the Ministry of Health supporting that as many patients as possible are diagnosed and starting treatment within the targets set in the CPPs and that follow-up plans are worked out for all cancer patients, when relevant?

Conclusion

It is Rigsrevisionen's assessment that the regions do not to the extent necessary ensure and the Ministry of Health does not adequately support that patients, who are suspected of having cancer or have been diagnosed with cancer, have timely access to cancer services. The survival rate for cancer patients in Denmark has improved and has over the past years come closer to the survival rates recorded in Norway and Sweden. However, the regions and the ministry do not have sufficiently focus on early detection of cancer patients in general practise. Moreover, some patients are not offered diagnosis and treatment in accordance with the statutory maximum waiting times. The regions and the ministry have great focus on the CPPs, but the personal follow-up plans have not yet been fully implemented. There are regional variations in relation to early detection, diagnosis, treatment and follow-up of cancer patients, which means that patients are not treated equally across the regions. The regions and the ministry's concerted action entails a risk that cancer is not detected and treated as early as possible and therefore progresses and becomes more difficult to treat.

Diagnostic investigation
If a patient has non-specific symptoms like, for instance, fatigue, weight loss, pain or anaemia, and the GP suspects that the patient may have a serious disease, the patient can be referred to further diagnostic investigation at the hospital, CT scanning or ultrasound examination.

It is Rigsrevisionen's assessment that the regions do not to the extent necessary support and the Ministry of Health does not adequately follow up early detection in general practice. The study shows that the Danish parliament, with the cancer plans and *The sooner - the better* initiative, have financed several efforts to improve early detection of cancer patients in general practise, for instance through supplementary training and access for GPs to refer patients to diagnostic investigation. The regions have launched initiatives that support the efforts, but there are regional variations in the scope of the initiatives in relation to, for instance, supplementary training and follow-up on accessibility in general practice. The ministry has not adequately followed up whether the regions have implemented the activities that are to support the initiatives. As a result, the regions and the ministry do not have sufficient knowledge of whether general practice is developing in the right direction in relation to ensuring early detection of cancer patients.

It is Rigsrevisionen's assessment that the regions do not adequately ensure and the Ministry of Health does not adequately support compliance with the maximum waiting times. The study shows that in the period from 2013 to 2017, the regions have reported approximately 3,000 patients to the Danish Health Agency who have either not been diagnosed or started treatment in accordance with the rules concerning maximum waiting times. Systemic faults such as, for example, misinterpretation of the rules in connection with the breast cancer-screening programme, are the cause of most of the reported incidents of non-compliance. Rigsrevisionen's review of 356 selected patient pathways from 2017 indicates that significantly more patients than reported by the regions wait longer than the rules on maximum waiting times stipulate. In consequence, considerably more patients than reported probably did not receive medical care in accordance with their patient rights, in 2017. It follows that the ministry's monitoring of the maximum waiting times is based on incomplete data. The ministry intends to enter into dialogue with the regions on their procedures in the area, a step that is welcomed and considered necessary by Rigsrevisionen.

It is Rigsrevisionen's assessment that the regions predominantly ensure and the Ministry of Health predominantly supports that the vast majority of patients are diagnosed and start treatment in accordance with the CPPs. The study shows that the share of patients who are diagnosed and starting treatment in accordance with the CPPs has been increasing over a couple of years. However, the share has dropped from 2016 to 2017 to a level where well over 20% of the patient pathways are longer than the CPPs. Some of them are longer for medical reasons or due to the patients' wishes. Yet, the regional variations indicate that there might be scope for improvement in the regions, where relatively few pathways are implemented in accordance with the CPPs for the individual types of cancer. The study shows that the ministry and the regions, through their comprehensive and detailed monitoring of the area, have ongoing focus on optimising the pathways of cancer patients by ensuring that challenges are identified, causes disclosed and corrective initiatives launched. However, the study also shows a possibility for the ministry to differentiate its follow-up on the CPPs further. It is not possible for Rigsrevisionen to determine whether the regions ensure and the Ministry of Health supports that follow-up plans are developed for all cancer patients when relevant, because national monitoring of follow-up plans has yet to be implemented.

The Ministry of Health and the regions have developed a comprehensive and detailed model for registration and monitoring of CPPs. Neither the early detection of cancer in general practice nor the statutory patient right to maximum waiting times receive the same level of attention. Rigsrevisionen recommends that the ministry together with the regions consider how they can further strengthen the focus on early detection and maximum waiting times to achieve a better balance between the various stages of the patient pathways without imposing additional administrative burdens on the hospitals.